

IMAGINE ID – Sleep difficulties in children with intellectual disability of known genetic aetiology

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IMAGINE ID

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Background

- Sleep disturbances are common in children with intellectual disability (ID)¹. However, previous literature has found that parents perceive these difficulties to have less of an impact compared to the behavioural and emotional difficulties resulting from their child's ID².
- Despite research showing that disturbed sleep impacts negatively upon both the child and their caregiver, sleep problems have not been investigated specifically in children with ID with a known genetic cause.
- This study aims to investigate sleep difficulties in children within IMAGINE ID, a UK national cohort study of children with ID of a genetic aetiology.
- Sleep difficulties and their association with the child's psychological wellbeing and caregiver stress will be investigated.



Methods

The DAWBA (Development and Wellbeing Assessment), a structured psychiatric interview was conducted online or via telephone with the caregivers of 1231 children aged 4-19 years with ID of genetic aetiology (Pathogenic CNVs assessed by array CGH) recruited through Regional Genetics Centres.

The following assessments were used:

- Sleep difficulties: Eating, Sleeping and Toilet training section of the DAWBA.
- Psychological wellbeing of the children: The Strengths and Difficulties Questionnaire (SDQ)
- Caregiver stress: The Everyday Feelings Questionnaire (EFQ) within the DAWBA.

Results:

- 37% of children in our cohort were found to have too little sleep, which is slightly higher than other reported prevalence rates of sleep problems in children with ID (range 25.5% - 36.2%).
- 42% had difficulties falling asleep, 66% were not settling in their own bed and 23% were reported to have night terrors or nightmares.

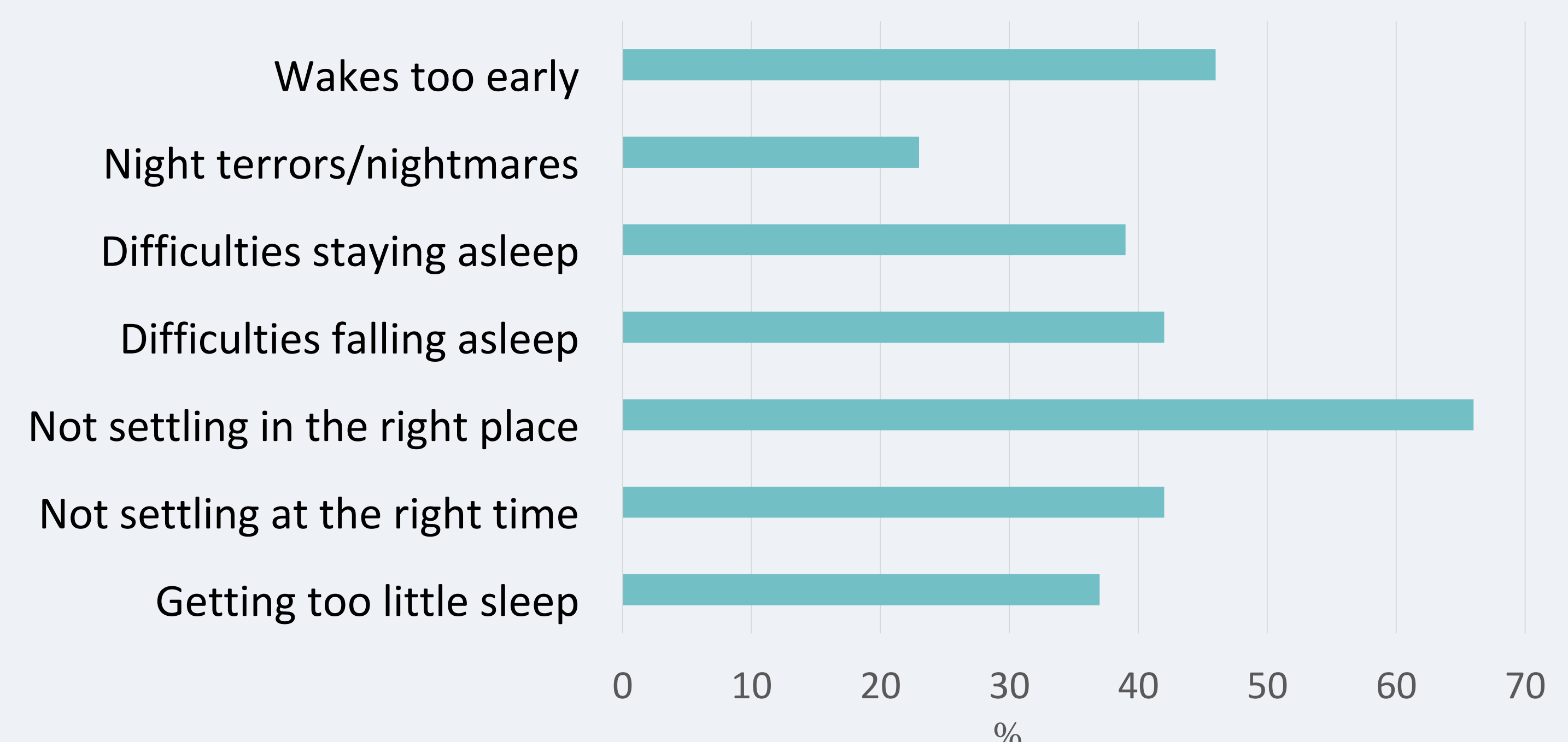


Figure 1. % of children in IMAGINE ID with sleep disturbances

- Caregiver EFQ total scores were significantly higher in those who reported their children as having insufficient sleep. Those reporting their child had enough sleep fell within the 'slightly raised' category (M=15.57) whereas those reporting their child had 'too little sleep' fell in the 'high' category (M=18.48), $p=0.00$.
- SDQ total scores were significantly higher in children reported to have insufficient sleep ($p=0.00$), falling in the 'very high' category (M=22.69).
- Sleep difficulties were found to have a significant impact on daily living ($p=0.00$).

Conclusion:

- Children with ID of known genetic aetiology in the IMAGINE ID cohort were found to have significant sleep difficulties. These sleep difficulties were associated with higher parental stress and poorer psychological wellbeing of the children.
- Given this association, a better understanding of the interaction between psychological wellbeing and sleep in children with ID of genetic aetiology is important in improving outcomes for these families.

References

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